



Erasmus+



Karolinska
Institutet

Ethics in Community based interventions and research with refugees and other vulnerable populations

Manuel Guerrero, PhD

manuel.guerrero@ki.se

manuel.guerrero@crb.uu.se

mguerrero@uchile.cl



UPPSALA
UNIVERSITET



FACULTAD DE
MEDICINA
UNIVERSIDAD DE CHILE



UNIVERSIDAD DE CHILE
CÁTEDRA DE
DERECHOS HUMANOS
VICERRECTORÍA DE
EXTENSIÓN Y COMUNICACIONES

Overview

- Moral conflicts and ethical dilemmas
- Historical background to contemporary ethics
- Community-based participatory interventions & ethics

Ethical dilemmas

- Moral conflicts:
 - When two actions -or the state of affairs that are the result of actions- both are desirable, BUT they exclude each other.
 - When two actions (state of affairs) are both undesirable BUT there is no way of excluding both.
- You need to choose! But how?



- **Factual statements/claims:**
 - Statements about what is/is not; state of affairs
- **Value statements:**
 - Statements saying that something is good/bad or better/worse than something else
- **Normative statements:**
 - Statements about what ought to (should/must) be/not be done (or what ought not to be the case)

***Ethics:** a theoretical reflection over moral issues - Systematisation, analysis and critique.*

Intuitive level - analytical level

Example: Cheating

- Imagine a situation in which you see a classmate cheating.
- There are several elements from a moral point of view that goes beyond just dislike:
 - Some people are *hurt* by the cheating.
 - There is *deception* in the situation.
 - Cheating seems to be *unfair* to those who don't cheat
 - Other expects the students to be *honest / loyal*, etc.

Ethics is about

- What is good/bad, better/worse (*value, the good*)
- What is the right/wrong thing to do (*the right action*)
- What makes us good persons (*virtuous character*)

Ethical analysis centers around

- Duties (obligations)
 - Rights
 - Consequences
 - Character
-
- Generate different ethical “theories”
 - Arguments and Alternatives

Major ethical theories

- Consequentialist theories
- Deontological theories
- Virtue-ethical theories

Consequentialist theories



"Create all the happiness you are able to create, remove all the misery you are able to remove."
- Jeremy Bentham

Consequentialist theories

- Judgment on alternative actions is based on their consequences
- What *kind* of consequences determines what kind of consequentialism (pleasure, material goods, beauty, preferences, flourishing lives)
- Monism vs. pluralism
- Consequences for *whom* also determines what kind of consequentialism (from egoism to utilitarianism)
- The good determines what is right
- Maximisation a common but not necessary aspect (minimisation)

Utilitarianism

- The more (utility) well-being for everyone an outcome contains, the better it is.
- The alternative that contains the greatest surplus of well-being is the one that ought to be chosen - all other choices are wrong.
- Equity -everyone's interests are given equal weight
- Self-sacrifice -the world should be a better place
- Effective altruism



"All the arguments to prove man's superiority cannot shatter this hard fact: in suffering the animals are our equals."
- Peter Singer

Criticism of utilitarianism

- How do we calculate the outcome beforehand?
 - U as a criterion for the best action
 - U as method to decide what action to take
- How do we measure (for example, happiness)?
- Goals to means - but which goals are moral?
- Is it really plausible to judge because of consequences?
- Too great demands on people? Should we not care for our nearest? Should we not value our own autonomy and freedom?

Test: The surgeon's dilemma

- You have six patients.
 - Five of them need an organ transplant.
 - Easily done if only there were organs at hand, which, unfortunately there aren't.
 - Your sixth patient is an ideal donator to all other five.
 - He suffers from a cold.
-
- Should you take his organs and thereby rescue the five but kill him?
 - What does consequential theory say about this?
 - What other arguments are applicable besides consequences?

Deontological theories



"Morality is not the doctrine of how we may make ourselves happy, but how we may make ourselves worthy of happiness."
- Immanuel Kant

Deontological theories - The nature of the act itself

- Wrong to kill since everyone has a right to live (rights)
- Act only according to a principle which at the same time can be imagined as an universal law (Kant's categorical imperative - unconditional obligation - test for universalisability)
- Treat others as you would like to be treated (the golden rule)
- Human beings must be treated never as a mere means but as also an end in themselves (a principle of human dignity against exploitation)



Tweet others as you wish to be tweeted.

Deontological theories

- Gr. 'deon' & 'logia'. The knowledge of obligation
- Is expressed in duties, principles or rules
- Often negative: Restrictions on what people can do
- What is right precedes what is good and is determined by the rules & principles
- A rule is good because it is our duty to follow it, not because of its consequences
- The best solution might be still be wrong
- Absolute principles: risk unsolvable clashes.
- *Prima facie*-principles: open up for ranking.

Pluralism in duties

- Duties of:
 - **Non-malificence**: do not harm
 - **Beneficence**: do good, benefit
 - **Justice**: treat equals equally
 - **Autonomy**: respect individual choices

(Beauchamp & Childress, Principles of Medical Ethics)

Criticism against deontology

- Why choose one principle over another?
- Might lead to bad consequences (Ex: Is it always wrong to lie?)
- How are we to minimise violations of right and dignity when to do so requires us to violate these very rights or dignities?

- What should I do? (Deontological theories & Consequentialist theories)
- What kind of person should I be? (Virtue ethics)

Virtue Ethics

@ethicsinbricks



"Excellence is an art won by training and habituation."
- Aristotle

Virtue ethics

- Motives for action and character traits in focus:
 - Virtue: good character trait (courage, honesty, generosity)
 - Vice: bad character trait, flaw character (greed, ruthlessness)
- A disposition or deeply rooted tendency to think and act in certain ways. Requires durability and stability.
- Central idea: The virtuous do the right thing, which will promote a flourishing life (*eudaimonia*).

Prudence

- The father of all virtues - the virtues should be founded upon prudence, upon the perfected ability to make right decisions.
- Virtue requires skill - a particular sensitivity for what is specific in the situation at hand, to see what is relevant in that situation.
- In prudential judgements, the circumstances must be weighed to determine the correct action.

Criticism against virtue ethics

- If we identify the virtuous we still cannot generalise - how else learn from them?
- Poor at giving guidance in specific cases
- If relative to culture, are we giving up rationality?
- The problem with incompatible directives - e.g. when honesty and compassion clashes.
- Needs a concept of the good life but what is a good life? What is the meaning of life?

Why is wrong to lie to a friend?

Consequences: She will be sad if she finds out or may be worse off if lied to.

Deontology: It is always wrong to lie to your friends.

Virtue: Good people do not lie to friends.

**Difference
between
the
theories**

Conclusion

- The theories all have difficulties in providing, by themselves, answers to question of value and of right action.
- Together they may provide us with a map of morally relevant features that meet in a certain moral dilemma.

Some requirements for a reasonable ethical analysis

- Must examine the expressions used to frame the dilemma and what role facts play
- Must consider the consequences of actions, including how wellbeing is affected
- Must consider people's motives and reasons for action
- Must acknowledge restrictions on how people can be treated and that they should be respected (regarding their own choices, e.g.)
- Must acknowledge that everyone involved must be considered and that all solutions be just
- Is your solutions consistent and can it be universalised?

Historical background to contemporary ethics

- Immediately after the horrors of the Second World War, the international community felt it necessary to strongly emphasise the notion of *human dignity* in order to prevent “barbarous acts which have outraged the conscience of mankind” from ever happening again (Preamble of the Universal Declaration of Human Rights of 1948, UDHR).
- The UDHR served as the cornerstone of the new international human rights system, which was grounded on the “recognition of the *inherent dignity* and of the equal and inalienable rights of all members of the human family” (Preamble).

The notion of human dignity

- Since 1948, the notion of *human dignity* operates as a central organising principle of the international human rights system.
- *The recourse to dignity* in this specific area reflects a real concern about the need to promote:
 - Respect *for the intrinsic worth of human beings* and the urgency to preserve the identity, and
 - The integrity of the human species against potentially harmful biotechnological developments.

“Inherent”

- The term “inherent” means “involved in the constitution, or essential character of something,” “intrinsic,” “permanent or characteristic attribute of something.”
- The idea expressed in this term, when it is accompanied by the adjective “human,” is that dignity is inseparable from the human condition.
- Thus, dignity is not an accidental quality of some human beings or a value derived from some particular personal circumstances such as the fact of being young or old, man or woman, and healthy or sick but rather something that all human beings possess by the mere fact of being human.

Equal rights

- An important consequence of the meaning that “human dignity” has in international law is that basic rights are equal for all: if human dignity is the same for all and the ground of human rights, then all human beings *possess equal basic rights*.
- This is the reason why discrimination, that is, the unjust distinction in the treatment of different categories of people is directly contrary to human dignity.

Rights derives from human dignity

- The third statement of international law stressing that rights derive from human dignity has also an important practical consequence:
- If basic rights are not given by authority, but are preexisting values which are inherent in every human being, then they cannot be legitimately taken away by government.

Community-based participatory interventions & ethics

- CBP investigates strategies designed to improve the health of individuals & populations
- Through
 - wider adoption of healthful behaviours
 - early detection & therapeutic practices
 - changes in public policies & institutional services to support healthier behaviours & community environments
 - mobilisation of community resources to address priorities related to quality of life & well-being
- CBP includes work & studies with defined populations in variety of settings, including
 - geographically defined communities
 - institutions
 - general public

Key principles

- Recognises community as a unit of identity
- Builds on strengths & resources within the community
- Facilitates collaborative, equitable partnership in all phases of the work & studies
- Promotes colearning & capacity building among all partners
- Integrates & achieves a balance btw research & action for the mutual benefit of partners
- Emphasises local relevance of public health problems & ecological perspectives that recognise & attend multiple determinant of health & disease
- Involves system development through a cyclical & iterative process
- Disseminates findings & knowledge gained to all partners & involves all partners in the dissemination process
- Involves long-term process & commitment

Israel, B. et al., 2003

Ethical issues in establishing a research community partnerships

- How to define a community?
- Who represents legitimately the community's interests?
- Who should control the research agenda & determine the research questions of interest?

An early step in building a research partnership is understanding how a community defines itself & its boundaries

-> Conduct a community assessment: Identify & engage formal & informal leaders & organisations with strong ties to the community of interest

-> Research should address an issue of concern to the community.

-> Ideally: People can assess their own needs & have the right to address them. More frequent: The researcher defines research topics & seeks community partners with shared interest.

-> How to navigate these challenges: Develop guidelines for collaboration (roles & responsibilities; rules for decision making; protocols for human subjects protection; stewardship of data; rules for coauthorship on publications & presentations for academic & nonacademic partners)

3 ethical principles:

- Respect for self-determination
- Liberty
- Action for social change

High risk & vulnerable communities

- Distrust due past injustices
- Important to ensure sensitivity in design, conduct & interpretation of findings
- New experiences: Establishment of community-based institutional review boards
 - Power to deny access to researchers & to control publication of research findings.

Ex. The American Indian Law Center's checklist for Indian Health Boards:

- What are the expected benefits of the research to the local community, to the individual research subjects, and to society as a whole?
- What are the assurances regarding the confidentiality of data? Will the community be identified in the research report?
- Will the researcher agree to satisfy community concerns in final drafts and the final reports?
- Is the researcher willing to attempt to find means of using local people and resources rather than import all resources?
- Is the researcher willing to deposit raw data in community designated repository or otherwise share the data with the community?

Methodological Issues & Ethics in Community-Based Interventions

- Choice of interventions strategies
 - Different levels of intervention. Focus on:
 - Intrapersonal factors (knowledge, attitudes, behaviour)
 - Interpersonal processes (family relationships, social support, social networks)
 - Institutional factors (organisations, norms, rules)
 - Community factors
 - Public policy.
 - Various strategies:
 - Educational & motivational
 - Organisations change
 - Policy directives
 - Laws
 - Economic supports
 - Community activation

Methodological Issues & Ethics in Community-Based Interventions

- Data collection techniques
 - Unit of observations (individuals, groups, organisations, communities)
 - Collected directly (interview, direct observation) or indirectly (reviewing records & archival sources)
 - Different methods (survey, self-administered questionnaires, telephone, face-to-face interviews)
- Study designs
 - Ex: Randomised, controlled experiments, community level interventions
 - organisation as the unit individuals may not have a personal choice about whether or not participate
 - Issue of “community consent” (vs traditional research participant consent)
 - “Respect for communities” as a new principle to supplement the individualistic interpretations of protecting human subjects (Belmont Report)

Ethical issues related to community-based interventions participants

- Respect for Autonomy
- Beneficence
- Justice
- Privacy
- Informed Consent and (Health) Literacy
- Conflict of interest
- Biased conduct & Interpretation of research

Special care should be exercised to protect the rights & interests of vulnerable populations, specially children, older adults, “minorities”, & high-risk populations.

Communities and individuals should be consulted and respected in every phase of the process.

Attention to 5 key areas

1. To increased sensitivity to ethnic & cultural habits and norms
2. To build trust through better communication
3. To considering communities as research partners not just sources of research subjects
4. To understanding and addressing important problems of communities
5. To developing guidelines for collaboration or operating procedures that clarify how the relationship will function.

Openness to understanding each others' views

Suarez-Balcazar, Y. et al., 2005

Thank you



Humans are meant to be loved. Objects are meant to be used.
Things go astray when objects are loved and humans are used.